

EQ-5D in Children RFP – Sept 2020

Validation of the EQ-5D-Y-5L

As in earlier calls, the Younger Populations Working Group (YPWG) calls again for proposals to carry out validation studies for the newly developed, extended version of the EQ-5D-Y in non-English speaking countries. Over recent years, a YPWG study team has developed an extended 5L version of the EQ-5D-Y. There are currently a few validation studies underway, mainly using the English version, but we are interested in receiving further proposals to test the measurement properties of the extended version (e.g. its sensitivity, validity, feasibility) in populations of children and adolescents in non-English speaking countries. We would particularly welcome proposals that aim to:

- Test the psychometric properties and performance of the extended EQ-5D-Y-5L in disease areas that cover the whole range of possible health impairments
- Compare the EQ-5D-Y-3L to the extended EQ-5D-Y-5L and therefore help to show whether instrument validity and sensitivity are improved in the extended version
- Propose studies with the following characteristics: longitudinal, variety of diseases, variety of severity levels, lower costs e.g. by co-funding by other funding sources

Further, it will be relevant to conduct reviews, secondary data analysis and – if needed and not too expensive – studies that aim for primary data collection (also in English-speaking countries) that compare the EQ-5D-Y instruments (-3L and/or -5L) with other child-specific instruments to gain information on the dimensions, items and the psychometric performance of the EQ-5D-Y instruments. Especially, comparisons of EQ-5D-Y and CHU9D are very welcome.

Note: if your study will be conducted in a country, where no EQ-5D-Y-5L translation is available yet, please be aware that the Office needs some time (at least 6-9 months) to produce a new language version of EQ-5D-Y-5L to support research. This should be considered when planning a project. Besides, you need to incorporate the costs for the translation process into the budget of your proposal. Further, currently all EQ-5D-Y-5L versions are beta versions. If the English source version changes, amendments to the language versions might be necessary as well.

Valuation of EQ-5D-Y-3L

A valuation protocol for the EQ-5D-Y has been agreed. The YPWG welcomes proposals for EQ-5D-Y-3L valuation studies. If EuroQol members are interested in conducting a national valuation study for the EQ-5D-Y-3L, they should contact Elly Stolk at the Office (stolk@euroqol.org). If a large number of applications are received, the YPWG and the Office will prioritise the requests. Requests for funding for valuation studies should also include a further (explorative) research question, in addition to the standard protocol. Candidate topics for consideration as research questions include:

- Framing/Wording of the valuation tasks which require respondents to take a ‘child health perspective’ (e.g. descriptor term, “a hypothetical child”, “a child you know”, “you as a child”, etc.)
- Whether and how the age of the child/adolescent described within the task affects valuations
- Impact of respondent background characteristics on the valuation of younger people’s health
- Impact of time/duration on the valuation of child health states
- Whether people’s valuation of child health states (vs. adult health states) reflects their wider views about how health care resources should be prioritized
- People’s priorities for children vs. adults
- Whether and how adult preferences for children and adolescent preferences differ
- Feasibility of TTO to obtain adolescent preferences

Conceptual work on youth valuation

The YPWG would like to invite proposals for conceptual work, e.g. a conceptual paper, about the implications of the common finding of the first valuation studies that the value range of EQ-5D-Y is narrower than the value range of EQ-5D (adult version). These findings likely reflect that for adult and children, people calibrate their time trade-offs differently (i.e. for the same quality of life improvement, they would sacrifice greater proportion of remaining lifespan in adults than in children). What does this mean for the comparability of TTO values of adult and child health states? If a child and an adult both report a health state that has been valued at 0.7, do they have the same quality of life? What are the consequences for cost-effectiveness analysis and the use of that evidence in decision making? Is it possible to compare or aggregate QALY gains incurred in different age groups?

Application of EQ-5D-Y (Y-3L/Y-5L)

Based on PubMed data, EQ-5D-Y seems to be used relatively rarely. The YPWG would like to encourage expanded use. It would be important to learn more about the usefulness and usability of EQ-5D-Y (Y-3L and/or Y-5L) in specific clinical areas/conditions. Studies of the most prevalent conditions are likely to be prioritised, however, studies of other relevant conditions would also be welcomed.

Further, in line with the research initiatives for adults, the use of the youth instruments in routine clinical practice, e.g. primary care, registers should also be a focus for research. Therefore, the YPWG calls for research on the usefulness and usability of EQ-5D-Y (Y-3L &/or Y-5L) as an outcome measure in routine clinical practice.

Testing an interviewer-administered version of the EQ-5D-Y

The EQ-5D-Y Interviewer Administered (IA) version has now been adopted as an approved version by the Executive Committee. There is still much that is not known regarding the comparative performance of the self-administered and the IA EQ-5D-Y versions. In order to guide users as to the choice of which form of administration should be utilized, the YPWG, in collaboration with the Version Management Committee (VMC) and the Descriptive System Working Group (DSWG), calls for proposals to compare the feasibility, reliability and other psychometric properties of the two forms of administration in younger and older children, both with and without health conditions. It would also be of interest to compare the results of one on one with Group administered responses (as in a class room setting) using the Self-complete versions with one group and the IA script combined with individual self-complete by the children.